Workshop 7: Community Outreach: Challenges in Implementation and Evaluation

Moderator: Francis Walker

New York State Department of Health AIDS Institute: Community Action for Prenatal Care Initiative (CAPC)

Roberta Glaros and Donna Parisi
AIDS Institute, New York State Department of Health

The New York State Task Force on the Prevention of Perinatal HIV Transmission, which consists of state and city agencies that deal with HIV/AIDS (women's health, family and community health, disease intervention, and alcoholism and drug abuse programs), has set a goal of reducing perinatal HIV transmission to 5% or less by 2004. For the task force's Community Action for Prenatal Care Initiative (CAPC), community coalitions have been formed and lead agencies selected in four areas; three in New York City and one in Buffalo.

Recognizing that strategies currently in place were not reaching the target population for perinatal HIV prevention, the coalitions seek to implement a comprehensive recruitment strategy that includes social marketing, a hot line for self-referral, referrals from community agencies serving high risk women, and enhanced street outreach. The coalitions are also responsible for developing an intake process at accessible sites in the community and coordinating a network of services needed by high risk women, including "user-friendly" prenatal care. The "intake" sites do pregnancy and HIV testing and transitional case management and refer clients to the service network, including long-term case management programs.

Rather than hire new staff, the project trains existing outreach staff to provide enhanced outreach. The worker in enhanced outreach is expected to complete 5 days of training, participate periodically in coalition-sponsored outreach projects, provide enhanced outreach to pregnant women encountered during routine outreach sponsored by their home agency, respond to hot line referrals from the lead agency, and, at the request of the prenatal provider, follow up on pregnant women lost to care.

The enhanced outreach worker:

- knows the barriers that keep pregnant women from entering prenatal care
- is familiar with resources for high-risk women within the community
- is familiar with the policies, procedures and staff at designated intake and prenatal care sites
- works through the social networks of women at risk within the targeted community
- seeks to build a trusting/helping relationship with individual clients, which may involve a series of encounters over time
- focuses on the women's immediate needs as she defines them.

Special training and activities are also provided for enhanced outreach supervisors.

There have been several challenges to implementation of enhanced outreach. Coalition building takes time and effort. There is a resistance to change in outreach practices and models, which don't typically

navigate people into care. The expectations of government funders may be too high initially. Training outreach workers to handle complex issues is a difficult task; issues must often be boiled down to simple concepts and practical steps for the client. There is a large turnover of outreach workers and supervisors, since generally they are not salaried employees on a career path. The final challenge is data collection.

Donna Parisi then presented an overview of how the project will be evaluated. New York State is collecting identifying information on the CAPC client up front, once she is found and brought into care either through outreach, the hotline or agency referral. They can then link with the rich sources of data already being collected to determine the following outcomes: the extent of prenatal care utilization, prenatal HIV testing, receipt of full 3-part 076 ARV regimen, perinatal HIV transmission, and birth outcomes (i.e., low birth weight).

Intermediate outcome measures include the number and percentage of women keeping their first referral appointment (information gathered through random record reviews at the sites where the CAPC client has been referred), and the knowledge, attitude, and behavior change resulting from the training of outreach workers (information collected by administering pre/post training questionnaires and a follow-up survey to determine what additional training the outreach workers need). An Intake Form has been developed to collect the following process measures: number of women completing intake form, source of intake (direct outreach, referral, media campaign, etc.), services received at intake (pregnancy testing, HIV testing, etc.), number and type of referrals provided, and number and percentage of women needing follow-up for missed referral appointments.

Challenges to evaluation include identifying the women that fit the CAPC model, obtaining identifying information at the intake site (women may not be willing to give this information), and standardizing the data collection protocol (who fills out the form? where?).

Key findings from the project thus far: a) the necessity of involving the targeted population in activities; b) ensure that the service system is established before implementing outreach activities; c) dedicating outreach workers to assist clients in navigating the system is desirable, but this will diminish the outreach workers' time and effectiveness in other activities; and d) consider the use of non-traditional setting or venues for education, for example, presenting information to women during the bus ride to Rikers Island.

New Jersey Experience

Eileen Girten and John Beil
New Jersey Department of Health and Senior Services

The New Jersey Perinatal Initiative was created to maximally reduce perinatal HIV transmission in the state. Three cities (Jersey City, Paterson and Newark) were selected based on zip code data that identified the highest pregnancy rates among HIV-infected women. The agencies in each city provide HIV, pregnancy and STD testing and other services via a mobile van. An outreach form was developed to capture essential risk factors, demographic data and services delivered. Based on 2,649 outreach encounters between inception of the program in July 2000 and January 2001, these were the key findings:

- Although risk factors identified included non-injection drug user, woman at risk through sexual

transmission, sex worker and injection drug user, males made use of the services provided on the van.

- The average age of the female client served in outreach was 30.5.

- Difficulties in collecting complete race and ethnicity data were encountered initially. However, additional technical assistance and training were provided to clarify the distinction between race and ethnicity to ensure complete data forms.

- The majority of outreach encounters took place in a neighborhood/street setting, especially with the availability of the mobile vans. Services provided on the van included HIV testing and counseling. Fifty-two females received HIV counseling and testing with three HIV-positive results. Surveillance is aware of those cases and is conducting a follow-up at present while the agencies are providing additional services to those clients.

- Over half of the outreach encounters involved a referral, primarily to more intensive services such as health education/risk reduction and prevention case management.

- Challenges in the coming year will be to increase HIV counseling and testing, STD testing, and pregnancy testing.

Illinois (Chicago) Experience

Michael Hunter and Margarita Reina
Chicago Department of Health

The project focus is on women not engaging or utilizing services in Chicago. Outreach is conducted in several neighborhoods and in Cook County Jail. Neighborhood outreach is conducted on the streets and from door to door. Women released from Cook County Jail are referred for services and tracked. The project utilizes transitional groups, sponsored by CBOs , to assist in developing a discharge plan for the women.

HIV Prevention for Incarcerated and Formerly-Incarcerated Women

Lori de Ravello, Division of Reproductive Health, Centers for Disease Control and Prevention

Public health interventions in correctional facilities are important for several reasons:

- Incarcerated people are at high risk for STDs, TB, HIV, and mental health problems.
- Correctional facilities are the primary source of health care for many arrestees and inmates.
- Interventions in jails and prisons can have high public health impact, as almost every inmate returns to their community.

Correctional facilities include jails and prisons. Jails are short-term facilities usually operated by a city,

county, or local government. Typically they hold arrestees awaiting trial or sentencing and inmates convicted and sentenced to less than one year. Fifty percent of arrestees are gone within 48 hours. Public health interventions must happen quickly or not at all. Most jails do very little screening–usually only for TB, sometimes for STDs, sometimes for pregnancy, rarely for HIV.

Prisons are longer-term facilities usually operated by the state or federal government. Here there is a greater opportunity to implement long-term public health interventions with follow-up. Prisons have a very comprehensive medical intake process, but the level and quality of ongoing medical care varies. Approximately 19 state Departments of Corrections have mandatory HIV testing of inmates upon entry into the facility; others vary in their policies.

In 1999, there were 90,668 female inmates in state and federal correctional facilities with the largest numbers in Texas (12,502), California (11,368), Florida (3,820), and New York (3,644). Incarceration rates for these female inmates were highest in Oklahoma, Texas, Louisiana, Mississippi, Nevada, and Hawaii.

The prevalence of AIDS (0.5%) in prisons and jails is more than 5 times that of the general U.S. population. The prevalence of HIV infection in prisons (2.3% –3.0%) and jails (1.2%–1.8%) is around 8-10 times and 4-6 times, respectively, of the rate in the general U.S. population. Seventeen percent of the total U.S. population with AIDS were released from prisons or jails in 1996; 13.1%–19.3% of the total U.S. population with HIV infection were released from prisons or jails in that same year.

In 1997, pregnancy testing of inmates in state and federal correctional systems was routine in 45%, on request in 84% and "as indicated" in 100%. In city and county systems, testing was routine in 29%, on request in 93%, and "as indicated" in 95%.

In that same year, HIV testing for pregnant female inmates in state and federal systems was mandatory in 45%, routine in 84%, offered in 100%, and "on request" in 14%. In city and county systems, testing for these women was mandatory in 29%, routine in 93%, offered in 95%, and "on request" in 22%. Ten percent of these systems had no policy on this issue.

Challenges to collaboration between correctional facilities and the public health establishment include:

- different priorities (security vs. health care)
- need for public health staff to remain objective and neutral, and not aligned with inmates or correctional staff
- flexibility and understanding on the part of public health staff
- commitment of resources
- space and confidentiality issues within the correctional system setting, and
- gaining approval for studies from institutional review boards.

Overcoming these challenges will require will require outreach projects to:

- invest significant time in planning and training public health staff, correctional staff, and outreach project staff
- tap into various public health resources
- develop respectful relationships and trust among inmates and correctional staff
- build infrastructure

- learn from other successful collaborations, and
- know the rules and regulations of the institutional review boards and be meticulous and patient.

HIV prevention for women released from correctional facilities involves discharge planning, insuring continuity of care (linkages and referrals), insuring access to HIV medications, and follow-up strategies based on the women's destination–whether it be release into the community, parole, probation, or transitional housing.

In 1997, a survey indicated that 92% of state and federal prison systems and 76% of city and county jail systems provide discharge planning for HIV-positive inmates that includes referral for various medical, social and psychosocial services. Although state and federal prison systems frequently (61%-78% depending on the service) referred discharged HIV-positive inmates to a variety of medical, social, and psychosocial services, they rarely (22%-35% depending on the service; only 1% made an appointment related to HIV medications) made the appointment for the inmate. The percentages for city/county jail systems for referrals (46%-66% depending on the service) and making appointments (17%-32%; 7% for HIV medications) are significantly lower. Referrals are obviously easier to make; however, it is likely that discharged inmates will feel more of a commitment or responsibility to keep an appointment that is actually made for them. Referrals may be ignored by the inmate for a variety of reasons.